



Health Technical Services Project



Discussion Papers on HIV/AIDS Care and Support

Psychosocial Support for People Living with HIV/AIDS

Prepared by
Helen Schietinger

Discussion Paper Number 5

June 1998

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The opinions expressed herein are those of the authors and do not necessarily reflect the
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About HTS

The Health Technical Services Project provides short- and medium-term technical assistance to USAID — specifically, to regional bureaus, regional and country missions, and the Office of Health and Nutrition in the Center for Population, Health and Nutrition of the Bureau for Global Programs, Field Support, and Research (G/PHN/HN). This technical assistance supports USAID programs in maternal and child health, nutrition, health policy reform, HIV/AIDS, and environmental health. HTS activities are concentrated in three broad technical areas: project design, policy and strategy, and evaluation and monitoring.

HTS's work is grounded in the four complementary values that guide USAID's efforts to reengineer its operations:

- a customer focus
- participation and teamwork
- empowerment and accountability
- management for results.

Foreword

The U.S. Agency for International Development seeks to develop and promote effective strategies for providing basic care and support to those affected by HIV/AIDS. This series of Discussion Papers on HIV/AIDS Care and Support represents a first step in this effort.

HIV/AIDS care and support mitigate the effects of the pandemic on individuals, families, communities, and nations. Such interventions are an important component of the overall response to HIV/AIDS because they increase the impact of prevention strategies and mitigate the negative consequences of the epidemic on the prospects for sustainable development.

This series of Discussion Papers covers several key issues related to care and support:

- Human rights and HIV/AIDS
- Palliative care for HIV/AIDS in less developed countries
- Preventing opportunistic infections in people infected with HIV
- Psychosocial support for people living with HIV/AIDS
- Community-based economic support for households affected by HIV/AIDS
- Responding to the needs of children orphaned by HIV/AIDS
- Systems for delivering HIV/AIDS care and support.

Each paper provides a preliminary review of some of the current thinking and research on these broad and complex topics. It is important to note that the papers are not meant to be comprehensive — time and resource constraints prevented the authors from reviewing all the relevant literature and from contacting all the people who have valuable experience in these and related fields. Nor have they been subject to technical or peer review. Their purpose is to stimulate a broad conversation on HIV/AIDS care that can help USAID define its future program activities in this area. We welcome your participation in this process.

Discussion Papers on HIV/AIDS Care and Support

Two additional papers on the topic of voluntary counseling and testing were prepared with USAID support:

- The Cost Effectiveness of HIV Counseling and Testing
- Voluntary HIV Counseling and Testing Efficacy Study: Final Report

These two papers are available from the IMPACT Project, Family Health International, 2101 Wilson Boulevard, Suite 700, Arlington, VA 22201; www.fhi.org.

Please direct your requests for copies of papers in the Discussion Series on HIV/AIDS Care and Support and your comments and suggestions on the issues they address to the Health Technical Services (HTS) Project, 1601 North Kent Street, Suite 1104, Arlington, VA 22209–2105; telephone (703) 516-9166; fax (703) 516-9188. Note that the papers can also be downloaded from the Internet at the HTS Project's web site (www.htsproject.com).

—Linda Sanei, Technical and Program Advisor,
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Psychosocial Support for People Living with HIV/AIDS

Psychosocial support is an essential aspect of HIV/AIDS care that mitigates the effects of the epidemic on the affected individuals, families, and communities. It includes a range of interventions to enable people to function in the face of the sometimes overwhelmingly adverse circumstances and problems caused by HIV and AIDS. These include accepting a positive HIV test, living positively with HIV, facing discrimination and stigma, coping with loss and grief, nurturing affected children, and, for health workers and counselors, combating burnout. Psychosocial care can be provided by professionals and nonprofessionals, including family, friends, neighbors, and others in the community. Therefore, it offers an opportunity for communities to interact constructively with people affected by HIV/AIDS, enhancing the likelihood of a positive rather than a negative community response to the epidemic. Because the skills required to provide psychosocial care can be taught to nonprofessionals, providing such care can be a sustainable, community-based activity that requires few if any outside resources.

P psychosocial support is considered an essential element of palliative care, which is care that strives to relieve, improve, or control symptoms and maximize the quality of care (Latimer and Dawson 1993; Sanei 1998). It includes a range of interventions that enable individuals and families to cope with adverse circumstances in their lives and with the sometimes overwhelming feelings caused by those circumstances. The adverse circumstances of HIV/AIDS include the shock of learning about a positive HIV test or a diagnosis of AIDS for one's self, spouse, or relative;

the stigma and discrimination that often attend HIV or AIDS; the long periods of illness; the burden of caring for sick family members; the disability or death of a productive adult family member and the loss of income that can result; and the powerful feelings of grief and mourning for the loss of one, and often many, family members. Psychosocial support lays the groundwork for families hit with HIV/AIDS to engage in constructive problem-solving to manage and plan for these and other immediate and long-term needs.

The type and intensity of psychosocial care and support that is needed varies with the circumstances faced by each family, but such support can encompass physical, emotional, and spiritual elements. In many cases, psychosocial care is provided alongside or grows out of other types of vital support. Mechanisms to provide this type of psychosocial support include support groups, volunteers who visit in the home and hospital, hospital outpatient clinics, pastoral counselors, and home-care programs — “in addition to providing medical and nursing care, most home care programmes offer information and counseling to individuals and sometimes their families to assist them in coming to terms with illness, death and bereavement” (Danziger 1994).

It can be provided by professionals and nonprofessionals, including those who have received training to provide such care and those who have not: physicians, nurses, and other health care workers; social workers; psychologists; health educators; clergy and other religious leaders; traditional healers and traditional birth attendants; and family, friends, neighbors, and others in the community.

Psychosocial support can encompass a wide range of activities, including:

- Formal activities designed to provide counseling, psychological care, and social and spiritual support, such as:
 - individual counseling: providing an opportunity for those affected to express their feelings and to talk about, prioritize, and solve problems and for others to express empathy and concern for them
 - group counseling: undertaking the activities related to individual counseling in a setting that provides opportunities for mutual support by other individuals experiencing the same problems
 - pastoral care: adding to the activities related to counseling various forms of spiritual support such as praying, singing, and reading inspirational texts.
- Formal medical activities designed primarily for other purposes, including
 - taking a medical history or conducting a physical exam in a clinic setting

- making home care visits to assist with activities of daily living that the person can no longer accomplish, ranging from household chores and farming to bathing and using the toilet.
- Informal activities whose primary purpose is not to provide psychosocial support, including
 - instrumental support, such as helping with household chores, cooking, caring for children, or helping with agricultural work
 - emotional support, such as talking, expressing empathy and sympathy, and offering advice.

THE IMPORTANCE OF PSYCHOSOCIAL CARE

1. Coming to Grips with a Positive HIV Test

There is widespread agreement among experts and institutions around the world that psychosocial support is an integral aspect of counseling associated with HIV testing, particularly to assist individuals in coping with a positive HIV test result. Such emotional and social support is in addition to the advice-giving and teaching that are also critical components of counseling and testing (Brugha 1994; Narain 1994; WHO 1995). According to Dr. Sandra Anderson at UNAIDS, “individuals can be empowered by knowing whether they are HIV–negative or HIV–positive — if social support is available” (Anderson 1994). According to the World Health Organization’s Global Programme on AIDS (WHO/GPA), psychosocial support is one of the two main components of HIV/AIDS counseling sessions. The other is an assessment of risks and planning for risk reduction, including developing decision-making capacity about options for prevention (WHO 1995).

When psychosocial support is not offered, health providers often do not tell their patients their HIV test results. In the Copperbelt in Zambia,

the unenviable task of breaking the news of a positive HIV test was the responsibility of doctors, sometimes with support from pastoral workers. Apart from being untrained for this highly sensitive task, doctors also rarely had the time to do it properly. As a result, many patients were never told that they were infected with HIV, and were discharged from hospital without knowing that they could pass the virus on to their

sexual partners. Other patients were simply informed that they were HIV-positive but were not offered any counseling to help them cope with the potentially devastating psycho-social impact of this information. (Mouli 1992)

To remedy this situation in Zambia, health care workers from every hospital department were trained as HIV/AIDS counselors, to enable them to provide the counseling support needed by patients (Mouli 1992).

At the Thai Red Cross Society Anonymous Clinic in Bangkok, trained counselors give test results. Somsri Sarangbin, a nurse and psychology graduate, has talked about the process:

Giving a positive result is always very hard. I share in the sadness of all those who learn that they are HIV-positive.... We don't tell people what to do, but we try to help them to cope with their problems, to plan their lives, and to seek additional support. (Sittirai and Williams 1994)

2. Learning to “Live Positively with HIV”

Peer support is a vital aspect of HIV care, and psychosocial support is the primary function of peer support. Peer support programs provide people who have learned that they are HIV-positive with an opportunity to see that others are surviving and living meaningful lives with HIV. The experience has provided hope and strength to countless individuals who were in despair about being HIV-positive.

There are examples of peer support programs on all continents and in all cultures. Perhaps the most widely known example is The AIDS Service Organization (TASO) in Uganda, which provides peer counseling as well as job training, shared meals, home visiting, and many other services (Hampton 1990). At TASO, the most important message for people learning that they are HIV infected is that they must, “live positively with AIDS.”

At the AIDS Programme of the Thai Red Cross Society, the Wednesday Friends' Club offers mutual support to people living with HIV. Typical of peer support organizations, it fulfills a dual purpose, providing peer support to people living with HIV and offering HIV/AIDS education to the community from people who can put a human face on HIV/AIDS (Sittirai and Williams 1994).

People with HIV or AIDS are in need of professional counseling to help them cope with their lives. Equally important, however, is the psychological and social support of other HIV-infected people, who know exactly what it is like to be told they are HIV-positive and to live with HIV on a daily basis. Support of this kind can help people with HIV recover their self-respect and self-confidence, lead socially useful lives, plan for their future, and, eventually, approach death with serenity.

“There are club members who have been HIV-positive for a long time,” says Khun Mee, Deputy Chairman of the club. “They’re like veteran soldiers, and they can explain to the newcomers how they’ve been able to live so long with the virus. They give them information and encouragement to keep on living. Before, a lot of people with HIV used to try to kill themselves, but that doesn’t happen so much now.” (Sititrai and Williams 1994)

In addition, the club organizes informal counseling for patients of the Immune Clinic at Chulalongkorn Hospital on Tuesday mornings. After the clinic, a group of club members visits friends who have been admitted to the hospital for treatment. Social gatherings and occasional outings to the seaside help to build feelings of friendship (Sititrai and Williams 1994).

3. Facing Discrimination and Stigma

Rejection of people who have HIV, or who are perceived to have HIV, occurs within couples, extended families, communities, workplaces, health care settings, and at international borders. Experiencing such discrimination can be emotionally, socially, and physically devastating. Psychosocial support is essential to enable victims of discrimination and rejection to continue functioning in settings that were once safe but are now hostile. HIV/AIDS programs around the world have had to provide advocacy services to respond to discrimination, emergency housing for people who have lost their homes, and protection for people who have been victims of violence. However, programs also provide assistance in rebuilding and maintaining a positive self-image in social settings that erode people’s confidence and sense of self-worth. Psychosocial support is an important aspect of programs that assist people whose human rights have been violated. (Danziger 1994)

Stigma is also a universal aspect of HIV/AIDS. People in all countries hide their HIV status because they fear being discriminated against or abandoned by their families and

communities. Somewhat paradoxically, interacting with people living with HIV/AIDS (PLWHAs) is the most effective means of countering discrimination and rejection and promoting acceptance of them. The emotional strength that peer support programs can provide to PLWHAs often empowers them to disclose their HIV status to families and others in the community.

In Katmandu, Nepal, people with HIV recently spoke out against such prejudice and discrimination. As one spokesperson with HIV explained, “Our aim is to spread the message — don’t fight people with AIDS, fight the disease instead.” The city’s first support group now has nearly 50 members, who receive counseling, medical care and advocacy. (AIDSLINK 1998)

4. Coping with Loss and Grief

Psychosocial support enables individuals and families to cope effectively with the continuous stream of losses related to HIV/AIDS. As HIV progresses, it causes gradual and unrelenting loss of function. People lose their physical strength and mobility, cognitive abilities, and, ultimately, the ability to function in their jobs and community. They lose their physical attractiveness and sexual ability. Family dynamics change as they become dependent for care on those for whom they formerly cared themselves.

The families of adults who are ill must struggle through diminishing household productivity and a loss of household income. The burden of caregiving, which usually falls to women, can take other adults away from productive responsibilities, which adds to the families’ financial stress.

Both the individuals who are infected and the families who are affected need psychosocial support to cope with such loss. In particular, they need assistance in planning for the future, including making wills and selecting guardians for their children. In short, psychosocial care is an essential element of support for individuals and families in their relentless downhill battle with HIV/AIDS.

Ultimately, people affected by HIV/AIDS need psychosocial support to help them manage the grief that results from the death of loved ones. Often this comes in the form of spiritual support provided by religious leaders and members of their congregations, “through the use of prayer, solidarity and the comfort which clergy can provide” (Danziger 1994). Communities can also provide important support by carrying out the comforting rituals that surround death. Activities such as bringing food to the bereaved family, sitting with the family at the wake, and participating in

funeral rites are all part of the community's expression of sympathy and support that enable the family to cope with their loss and grief.

5. Responding to the Needs of Affected Children

Addressing the psychosocial needs of vulnerable children for nurturing, socialization, and education, among other things, is a vital component of ensuring the welfare and productivity of the next generation. Supporting family and community structures to meet these needs prevents children from being abandoned, or from becoming street children, delinquents, or criminals.

One of the six intervention strategies outlined in a recent report on orphans was to assist children, families, and communities affected by HIV/AIDS by strengthening the capacity of families to cope with their problems (Hunter and Williamson 1998a; see also Hunter and Williamson 1998b). This involves such activities as improving their ability to generate income, ensuring their access to health services, and responding to their psychosocial needs:

Children's psychosocial distress begins with a parent's illness, and they are left emotionally and physically vulnerable by the death of one or both parents. They may suffer lingering emotional problems from attending to dying parents and seeing their parents die....

Protracted illness and the eventual death of parents have profound psychosocial effects on children, but these receive less attention than the more visible problems they face. Most measures to address psychosocial needs among children affected by HIV/AIDS do not require separate new programs but can be incorporated into school, health, and other activities. Approaches include helping infected parents play normal parental and social roles and giving children opportunities to talk about their fears.

In addition to physical and material support, a vitally important aspect of strengthening family coping capacities is providing emotional support and encouragement. Friends, neighbors, families, members of the families' religious communities, or cooperative associations can help build a sense of hope and possibility through periodic visits. This can

also be an important component of outreach programs that support home-based care. (Hunter and Williamson 1998a)

In communities that are heavily impacted by HIV/AIDS, attitudes of hope and solidarity are vital to sustaining the ability of extended families to support people with HIV or AIDS, particularly as the epidemic continues to take a heavy toll in a community (Seeley et al. 1993). Extended families are often cited as the mainstay of society in developing countries, the one institution that continues to support people living with HIV, especially children who are orphaned. However, as early as 1990, it was noted that in the most highly affected areas of Africa the ability of the extended family to care for the dying and to foster the resulting orphans was being strained (Hunter 1990). Not only do families need material support, many “need moral and practical support, in the form of encouragement, reassurance and practical advice on how best to care, in order to provide adequate care for their sick members” (Seeley et al. 1993).

With the advent of AIDS, some strands in the extended family safety net have snapped. AIDS deaths are highest among people aged between 25 [and] 45, the age group who in the past would have been most likely to accept their orphaned nieces or nephews into their own homes. Today, many of these uncles or aunts have already died of AIDS, or are chronically ill and close to destitution. Others have already accepted the orphans of other deceased relatives into their homes and simply cannot afford to take any more. In communities where hardly a week goes by without a neighbour dying of AIDS, attendance at funerals is also a huge drain on the limited time and money available, and reduces the resources that otherwise might be available for supporting members of the extended family. (Mukoyogo and Williams 1991)

Thus, orphans become the most vulnerable individuals in the community. They often lack proper supervision and nurturing and are taken out of school to care for sick and dying family members or to generate income. Their risks of poor health are increased by reduced nutritional status, poor access to health care, and exposure to disease. Their long-term income-earning potential is decreased by the gaps in their education. And they may become socially alienated from other members of their communities.

Delinquency problems already exist in communities where large numbers of orphans have migrated, live in groups with no supervision, steal from the market place to feed themselves, and are reportedly used by older persons for petty theft and other criminal activity. (Hunter 1990)

6. Combating Burnout among Health Care Workers and Counselors

The HIV/AIDS epidemic has placed tremendous strains on health care workers, who themselves often need psychosocial support to continue their difficult work (Buwalda et al. 1994). In developing countries, the stress is not only a result of the increased number of people who need health care services, but also the health care workers' inability to meet their patients' needs. Service providers who have no medicines to offer to their patients and who have no time to provide counseling and support feel overwhelmed and inadequate.

The nurses probably recognize the need for a well-functioning AIDS programme in the District, but still find it difficult to introduce counselling, which is so different from other medical work. They definitely need good support, more resources, more training and a very consistent programme. (Buwalda et al. 1994)

Two common care interventions support health care workers in being able to care for people with HIV/AIDS and their families:

- Training programs to enhance counseling skills: Training materials and resources for counselor training programs are available from a number of sources, including the World Health Organization (WHO 1994; WHO 1995). Training materials and resources for training volunteers to be counselors are also widely available.
- Programs to provide volunteers in hospitals and clinics to meet the emotional and educational needs of PLWHAs and their families: Of particular value are programs that develop peer counselors — people with HIV who meet with newly diagnosed patients to address their fears and their questions. TASO in Uganda has written materials and developed a training video that is available through the Strategies for Hope series published by ACTIONAID in London (Hampton 1990).

PSYCHOSOCIAL SUPPORT AS A FOUNDATION FOR HIV/AIDS PREVENTION

Behavior Change Theory

The models of behavior change theory used in HIV prevention all incorporate some aspect of psychosocial support, defined broadly as personal and social support of the individual that enhances positive coping mechanisms and behaviors. The cognitive models of behavior change, based on the theory that knowledge motivates behavior change, have been fortified with concepts from the more complex models that describe behavior change as a process involving not only knowledge about health risks, but a matrix of attitudes and beliefs about the self in society, embedded in a series of contextual variables related to social support and societal norms.

The Health Belief Model, perhaps the most widely used cognitive model of behavior change in health education, predicates behavior change on the beliefs of individuals regarding their perceptions about their susceptibility to a disease, about the severity of the disease, and about barriers to protecting themselves from the disease (Leviton 1989). Although this model is based primarily on knowledge about health risk, specific variables thought to predict behavior are psychosocial in nature:

- cues to action, such as physicians' advice or self-perceived symptoms
- demographic, structural, and social/psychological factors that enable behavior, particularly the supportive nature of the individuals' environments. (Leviton 1989)

Another cognitive model, the Theory of Reasoned Action, identifies intention as the main influence on behavior, and sees intention as being influenced not only by individuals' beliefs about the behavior, but their beliefs about what significant others think about the behavior and how much they value the opinions of others (Leviton 1989). Here we see aspects of psychosocial support as primary variables that can be changed to enhance the likelihood of behavior change.

Social Cognitive Theory adds the concept of self-efficacy — individuals' perceptions about their ability to perform a behavior — to the theory of behavior change (Bandura 1986). The higher the perceived self-efficacy, the greater the likelihood that the individual will attempt to change his or her behavior. Numerous psychosocial interventions can enhance self-efficacy, including providing role models with whom individuals identify who are successful in changing behaviors, social support that occurs in peer support groups or training of peer counselors, and skills development

(for example, group and individual counseling in which individuals have an opportunity to practice new behaviors).

A dynamic temporal dimension has been added to these theories, best exemplified in the Transtheoretical Model of behavior change, which posits that behavior change is an ongoing process in which individuals move through specific stages of change (precontemplation, contemplation, preparation, action, and maintenance). The processes of change are also affected by two other dynamic variables, Decisional Balance and Situational Temptation (Prochaska 1988; Fava, Velicer, and Prochaska 1995). Individuals who are in each stage of the behavior change process require specific interventions related to that stage in order to move on to the next stage in the process (with continued adherence to the target behavior as the final stage in the process). The processes of change, or interventions, are categorized as both experiential activities (i.e., Consciousness-Raising, Environmental Reevaluation, Self-Reevaluation, Social Liberation, and Dramatic Relief) and behavioral activities (Helping Relationship, Self-Liberation, Counter-conditioning, Reinforcement Management, and Stimulus Control).

According to this theory, for HIV prevention to be effective, a menu of interventions is needed to target individuals who are at each stage of the behavior change process. For example, counseling and testing may utilize consciousness-raising or self-reevaluation, and the helping relationship, depending upon the stage of change of each individual, because each intervention will be successful only with individuals who are in a particular stage of change, client and community assessments can enable planners to target interventions to specific individuals and groups.

An overarching lesson can be applied to HIV prevention from the body of theory regarding behavior change: psychosocial support mechanisms ranging from the use of individual helping relationships to the reinforcement of social norms and beliefs are important aspects of HIV prevention.

Psychosocial Support Interventions that Promote Prevention

Counseling and Testing

Psychosocial support as a component of palliative care strongly fosters HIV prevention all along the disease continuum. At the beginning of the continuum, psychosocial support is a critical component of HIV counseling and testing programs (WHO 1994; WHO 1995). Here, one function is to assist individuals in coping constructively with a positive HIV test result. However, another essential function is

to facilitate a change to safer behaviors among both HIV–positive and HIV–negative individuals.

Counseling and testing has been shown to be an effective intervention in reducing risk behavior in developing countries (Sangiwa et al. 1998). One research study compared a voluntary counseling and testing (VCT) intervention to a standardized health information (HI) intervention and found that risk reduction with nonprimary partners was significantly greater among those assigned to VCT. The group also found evidence that couple counseling appears to be a potent intervention for stimulating safer sexual behaviors. In a study of married couples randomized to VCT and HI, both interventions were successful in reducing reports by couples of any sexual intercourse and any unprotected intercourse with their spouses, but with a trend toward more change among VCT couples. According to the authors, “These results point out the importance of couple counseling as it provides the two partners with a chance to negotiate a risk reduction plan with the assistance of a counselor” (Kamenga et al. 1998).

Another situation in which couples counseling can occur is in home care. Home visits provide opportunities for health care providers and counselors to work with families, and specifically couples, in private circumstances under which couples counseling can and does occur (Campbell and Williams 1990).

Peer Support

Psychosocial support interventions that provide peer support to PLWHAs and people at high risk for acquiring HIV also play an important role in HIV prevention. Peer support groups or peer volunteers who visit PLWHAs in clinics or hospitals provide a new perspective for newly diagnosed individuals — namely, that PLWHAs can continue to live and find meaning in their lives. Peer support interventions counteract feelings of isolation, fear, and despair and provide role models for “living positively” with hope and purpose despite the specter of an unknown future. These interventions help individuals cope with HIV and empower them to engage in safer behaviors. In addition, they develop social norms within the group that promote safer behaviors.

PLWHA Participation in Community Education Activities

An equally important prevention-related objective of psychosocial support is the empowerment of PLWHAs to participate in community education that puts a human face on HIV/AIDS. When people with HIV/AIDS are able to disclose their status publicly, individuals in the community who identify with them become convinced that HIV might actually affect them. The closer the PLWHA resembles community

members, the more likely they are to be convinced. In the terms of the Health Belief Model, their motivation to change increases because they believe that HIV is a personal threat.

Public disclosure by PLWHAs also contributes to community acceptance of PLWHAs, reducing discrimination against them. This in turn decreases their marginalization and reduces their need to participate in risky behaviors for survival.

Emotional and Spiritual Support

The provision of emotional and spiritual support through volunteer, pastoral, and professional counseling and support groups has important prevention objectives, which are also supported by the provision of medical or nursing care or social services. In particular, the development of a trusting relationship between client and counselor is an important component of all of these psychosocial interventions. Also, these interventions create a social context in which the norm is safe behavior, which can be reinforced by the physical environment (i.e., condoms in the waiting rooms, HIV education posters on the walls).

The social/psychological factors that “enable” behaviors are all part of many environments in which HIV/AIDS care is delivered. In most societies, PLWHAs do not encounter supportive environments until they are engaged in care. In other places, they anticipate rejection and stigmatization if their diagnosis is discovered.

Assistance to Orphans and Other Vulnerable Children

The set of psychosocial support interventions that provide nurturing, socialization, and education to vulnerable children, especially orphans, contributes to HIV prevention on a long-term basis by reducing the children’s chances of becoming socially marginalized and engaging in risky behaviors. Provided with opportunities to grow and develop normally within the community and to receive an education, they are much less likely to become outcasts who must depend upon activities such as commercial sex work or drug trafficking to survive.

Preventing Burnout among Health Workers and Counselors

Finally, providing psychosocial support to health care workers contributes to HIV prevention by enabling them to cope with the stress of their difficult work. This can include support groups for health care workers in heavily impacted health facilities and training to provide counseling skills. Health workers who have access to these types of interventions are better able to provide the psychosocial support to their

patients that encourages safe behavior. Health workers who are emotionally drained and overworked find themselves unable to “go the extra mile” to provide HIV prevention education to all their patients during their brief encounters with them.

In summary, HIV/AIDS prevention requires social change in two areas:

- **Community norms:** Two examples of community norms that promote prevention are social acceptance of condoms and an expectation of sexual abstinence outside of the primary relationship.
- **The balance of power among groups of people:** An example of a balance of power that promotes HIV prevention is a social expectation that women have control over their sexual relationships and their economic well-being. This empowers women to refuse to engage in unsafe sexual relationships and to avoid being economically dependent upon a sexual partner with whom they might be forced to engage in unsafe sex.

Psychosocial support interventions that reinforce this contextual framework promote care (e.g., the ability of people to cope with effects of the epidemic) and prevention (e.g., the ability of people to protect themselves from HIV infection).

CONCLUSIONS

Psychosocial support is an essential aspect of HIV/AIDS care that enables individuals and families to function in the face of their problems, enhancing their ability to respond to the challenges that confront them. Psychosocial support can counteract the denial that prevents individuals and families from facing a positive diagnosis. It lays the groundwork for constructive problem-solving to manage the immediate health, nutritional, and other needs of the family and to plan for the long term. It provides an opportunity for the community to interact with people affected by HIV/AIDS constructively, enhancing the likelihood of a positive rather than a fear-based community response to the epidemic.

In short, psychosocial support plays critical roles in mitigating the effects of the epidemic on individuals, families, and communities and in preventing further HIV transmission. This type of care involves skills that can be taught to nonprofessionals within the community and therefore represents a sustainable activity that can require little or no outside support.

Annex A: References

- AIDSLINK. 1998. "Nepal: Seek Cure Prejudice," *AIDSLINK* 49. Washington, DC: National Council on International Health (January/February).
- Anderson, Sandra. 1994. "Community Responses to AIDS," *World Health Forum*. Geneva: World Health Organization.
- Bandura, A. 1986. "Self-Efficacy Mechanism in Human Agency," *American Psychologist* 40:359–73.
- Brugha. 1994. "HIV Counseling and Care Programmes at the District Level in Ghana," *AIDSCare* 6(2):129–37.
- Buwalda, P., D. J. Kruijthoff, M. de Bruyn, and A. Hogewoning. 1994. "Evaluation of a Home-Care/Counseling AIDS Programme in Kgatleng District, Botswana," *AIDS Care* 6(2):153–60.
- Campbell, Ian D., and Glen Williams. 1990 (rev. 1992). *AIDS Management: An Integrated Approach*. Strategy for Hope No. 3. London: ACTIONAID.
- Danziger, Renee. 1994. "The Social Impact of HIV/AIDS in Developing Countries," *Social Science and Medicine* 39(7):905–17.
- Fava, Joseph L., W. F. Velicer, and J. O. Prochaska. 1995 "Applying the Transtheoretical Model to a Representative Sample of Smokers," *Addictive Behaviors* 20(2):189–203.
- Hampton, Janie. 1990. *Living Positively with AIDS*. Strategies for Hope No. 2. London: ACTIONAID.
- Hunter, Susan. 1990. "Orphans as a Window on the AIDS Epidemic in Sub-Saharan Africa: Initial Results and Implications of a Study in Uganda," *Social Science and Medicine* 31(6):681–90.
- Hunter, Susan, and Williamson, John. 1998a. *Children on the Brink: Strategies to Support Children Isolated by HIV/AIDS*. Arlington, VA: Health Technical Services (HTS) Project for USAID (January).

Discussion Papers on HIV/AIDS Care and Support

- Hunter, Susan, and Williamson, John. 1998b. *Responding to the Needs of Children Orphaned by HIV/AIDS*, Discussion Paper on HIV/AIDS Care and Support No. 7. Arlington, VA: Health Technical Services (HTS) Project for USAID (June).
- Kamenga, M.C., S. Gregorich, G. Sangiwa, C. Furlonge, D. Balmer, T. Coates, and the VCT Study Group. 1998. *Impact of HIV Counseling and Testing on Married Couples in Three Developing Countries: Results from the Voluntary HIV Counseling and Testing Study*, abstract presented at the XII International HIV Conference, Geneva.
- Latimer, E. J., and H. R. Dawson. 1993. "Palliative Care: Principles and Practice," *Journal of the Canadian Medical Association* 148(6):933–34.
- Leviton, Laura C. 1989. "Theoretical Foundations of AIDS-Prevention Programs," in R. O. Valdisseri, ed., *Preventing AIDS: The Design of Effective Programs*. New Brunswick, NJ: Rutgers University Press.
- Mouli, Chandra V. 1992. *All Against AIDS: The Copperbelt Health Education Project, Zambia*, Strategies for Hope No 7. London: ACTIONAID.
- Mukoyogo, M. Christian, and Glen Williams. 1991. *AIDS Orphans: A Community Perspective from Tanzania*, Strategies for Hope No. 5. London: ACTIONAID. (June).
- Narain, Jai P., and S. Pattanayak. 1994. "Management of Patients with HIV/AIDS: Need for Comprehensive Care," *Journal of the Indian Medical Association* 92(1):11–14 (January).
- Prochaska, James O., W. F. Velicer, C. C. DiClemente, and J. Fava. 1988. "Measuring Processes of Change: Applications to the Cessation of Smoking," *Journal of Consulting and Clinical Psychology* 56(4):520–28.
- Sanei, Linda. 1998. *Palliative Care for HIV/AIDS in Less Developed Countries*, Discussion Paper on HIV/AIDS Care and Support No. 3. Arlington, VA: Health Technical Services (HTS) Project for USAID (June).
- Sangiwa, G., D. Balmer, C. Furlonge, O. Grinstead, M. C. Kamenga, T. Coates, and the VCT Study Group. 1998. *Voluntary HIV Counseling & Testing (VCT) Reduces Risk Behavior in Developing Countries: Results from the Voluntary Counseling and Testing Study*, abstract presented at the XII International HIV Conference, Geneva (June).

Psychosocial Support for People Living with HIV/AIDS

- Seeley, J., E. Kajura, C. Bachengana, M. Okongo, U. Wagner, and D. Mulder. 1993. "The Extended Family and Support for People with AIDS in a Rural Population in South West Uganda: a Safety Net with Holes?" *AIDS Care* 5(1):117–22,
- Sittitrai, Werasit, and Williams, Glen. 1994. *Candles of Hope: The AIDS Programme of the Thai Red Cross Society*, Strategies for Hope No. 9. London: ACTIONAID (July).
- WHO. 1995. *Counseling for HIV/AIDS: A Key to Caring, For Policy-Makers, Planners and Implementors of Counseling Activities*. Geneva: World Health Organization, Global Programme on AIDS, UN Document No. WHO/GPA/TCO/HCS/95.15.

Annex B: Acronyms

Below is a list of the acronyms used in this report.

CBO	Community-based organization
GPA	Global Programme on AIDS (WHO)
HI	Health information
HTS	Health Technical Services Project
NGO	Nongovernmental organization
PLWHA	Person/people living with HIV/AIDS
STI	Sexually transmitted infection
TASO	The AIDS Service Organization (Uganda)
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VCT	Voluntary counseling and testing
WHO	World Health Organization
WHO/GPA	World Health Organization's Global Programme on AIDS (replaced on January 1, 1996, by UNAIDS)

Annex C: Prevention and Care Dynamic of Psychosocial Care Interventions

Figure 1. Prevention and Care Dynamic of Psychosocial Care Interventions

Intervention	Immediate Beneficiary	Primary Benefit	Mitigating Effect	Prevention Benefit
Counseling with HIV testing	People living with HIV/AIDS (PLWHAs)	Enables them to cope with positive HIV test result	Can help find sources for care and support	Helps HIV–positive people respond to their status in a socially responsible manner, particularly by safe sexual behaviors
	People with negative HIV test results	May prompt them to change unsafe behaviors	Relieves stress associated with not knowing their HIV status	Can prompt HIV–negative people to seek information and adopt safer behaviors
Peer support programs	<ul style="list-style-type: none"> ▪ PLWHAs ▪ Members of specific affinity groups (e.g., high-risk youth) 	<ul style="list-style-type: none"> ▪ Relief and comfort from social support of others who are HIV–infected ▪ Can incorporate knowledge of HIV status into personal values, goals, and actions 	Can become empowered to seek appropriate care, live positively with HIV/AIDS, and thus remain productive longer	Helps people respond in socially responsible manner to their HIV status, including taking measures to avoid infecting others, reaching out to support other PLWHAs, and provide HIV/AIDS education in the community
Volunteer, pastoral, and professional counseling, support groups, and emotional support provided by health care providers	<ul style="list-style-type: none"> ▪ PLWHAs ▪ Families ▪ Caregivers 	Enables them to cope with hardships and grief throughout the disease process	Helps prevent some of the stress that can accompany HIV/AIDS	<ul style="list-style-type: none"> ▪ Enables people to sustain safe behaviors despite stresses of their problems ▪ Reduces HIV/AIDS stigma in the community

Figure 1. Prevention and Care Dynamic of Psychosocial Care Interventions

Intervention	Immediate Beneficiary	Primary Benefit	Mitigating Effect	Prevention Benefit
Community education to “put a human face” on HIV/AIDS	PLWHAs	Reduces discrimination and stigma associated with HIV/AIDS	Helps build more supportive community attitude toward PLWHAs and those perceived to be HIV-positive	When they are less stigmatized, PLWHAs are less socially vulnerable and less likely to practice risky behaviors
	Members of the community, especially those at high risk for HIV	Seeing people that resemble themselves infected with HIV helps people take the risks seriously	Helps de-stigmatize PLWHAs	Prompts people to adopt safer sexual behaviors
Programs to provide nurturing, socialization, and education to children	<ul style="list-style-type: none"> ▪ Children of PLWHAs ▪ Orphans ▪ Other vulnerable children in community 	Helps children affected by HIV/AIDS grow and develop normally	Reduces the risks that such children will suffer poor health, be at higher risk for disease or crime, or be pulled from school	Children who are less socially and economically vulnerable have lower risk of becoming infected by HIV
Programs to prevent burnout among health workers and counselors	Health care workers and social service workers who care for PLWHAs	Helps health care and social workers provide effective care to PLWHAs	Helps those who care for PLWHAs cope with high stress and emotional demands of their work; enhances all health care	Workers who are not overstressed have more energy and motivation to provide education and counseling to all patients, which can help motivate some patients to practice safer behaviors